Author's response to reviews

Title: A telephone survey of factors affecting willingness to participate in health research surveys

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Author's response to reviews: see over
Reply to reviewer

Dear Editors,

Pleas find our reply to the reviewer. We have answered each point in italics below and made changes to the paper accordingly.

Kind regards Debbie Glass

Reviewer’s report
Title: A telephone survey of factors affecting willingness to participate in health research surveys
Version: 2 Date: 18 June 2015
Reviewer: Kristen Malecki

Reviewer’s report:
Major Compulsory Revisions

Overall, I feel this paper still lacks detail in background and methods sections regarding the description of cohorts and target populations for this study which I feel limits its impact and contribution to the field.

Also, authors do not include a lot of detail on how findings are at all novel or unique and or the significance of this work, some additional statements on the gap being addressed by this work in Australia and how findings will be used by the research team could really strengthen this paper.

We have added a section to the end of the discussion summarising how our findings could help other studies to improve recruitment.

Lines 78-79 – Here is a place in the methods where overall comments could be addressed more directly.

We have clarified the purpose of the samples here:
“In order establish willingness of the general Australian population to participate in health surveys we chose a random sample of the Australian population. We also solicited views from individuals who had previously taken part in health surveys to identify whether this had led to a change in willingness to participate.”

For example in lines pg. 90-94 – what were the goals of the cohort? Why did participants originally participate and how were they selected, some of this context is important for interpreting the results.

We have added information about the cohort and case control studies.

Cohort
“The cohort was a cancer and mortality study of approximately 18,000 workers in the Australian petroleum industry of whom 90% were male.” Employees had been
enrolled in the cohort by participating in face to face interviews in at least one of four surveys between 1980 and 2000 which took place during work time with help from the site medical services. Over 90% of eligible employees participated in the cohort. Refusal to participate was uncommon. The major cause of non-participation was difficulty in locating individuals because of temporary absences such as sick leave or annual leave.\[15]\]

Case-control study added info: The number of cases and text as follows:
“The patients in WABOHS were men and women aged between 40 and 79.\[17]\]

Lines 161-168 – It needs to be made more clear that the paper is looking at future willingness to participate among past cohort and case-control studies.

We have clarified line 164 (now line 174). We now say:
“Nearly two-thirds (61%) of the general population sample stated that they would be willing or very willing to participate in health surveys and only 11% said that they were generally unwilling (Table 3). A higher proportion, 83%, of the participants drawn from the cohort and case control study were willing to participate in another study.”

Line 173 now 185 we have revised to say
“Similar results in terms of male/female, education, and remoteness were seen for the case-control and cohort participants (Table 3) the one difference was that these individuals were not more likely to take part if they had a long term disease or disability.”

Paragraph 211-235 needs revisions for clarity, the newly added paragraphs need revision for clarity, hard to see what authors are saying.

In paragraph 211-235 now 227-257: we have edited sentences to improve clarity.

Line 199 now 211 reads
“In the case of the largely male cohort, the responders continued to be willing to take part in research, although men usually show lower interest in participating in health research than women, as seen among the general population participants in this study. Case-control participants had a higher participation rate in this survey than the cohort participants which may be a result of the shorter time between the case-control study and our survey. It may also reflect the reduced interest in participating in a study which is less personally relevant than the cohort study.”

Line 227, now line 243, we have also revised the following sentence to read.
“Researchers have suggested that factual willingness to participate in health research is greater than hypothetical willingness. That is, a higher proportion of people actually take part in research when asked than say they are willing do so in answer to a hypothetical question.\[27]\”

Discussion - here would be a place to discuss more directly how these results will be used in future research, or despite the findings being similar to other findings, why this study is particularly important for addressing issues related to survey participation.
We have added the following to the Discussion

“Newer survey methods such as web based questionnaires have advantages and disadvantages in comparison with traditional survey methods such as telephone or postal questionnaires but have been used considerably less commonly and there are concerns about nonresponse bias and reliability of the data collected by this method.

\[39\] Our study has provided contemporary information using an established method to inform future recruitment to health research studies. “

And

“Reduced participation over time has been encountered across all epidemiological study designs, in terms of non-response as well as refusal, and a low response rate may reduce the statistical power and generalisability of results to the wider community. Therefore it is important to maintain current understanding of people’s willingness to participate in health research and factors that affect their willingness to participate.

Despite declining participation rates, the fact that participation in health research studies is seen positively is a good sign. Our findings have the following are implications for future research with a view to improving participation in health research studies:

- Ensure that the bone fide credentials of health researchers or their institutions are identified early in the process to distinguish them from telemarketing ‘surveys’
- Ensure that the reason is communicated clearly and is understandable to participants.
- The source of funding should be identified, and if the funding source is not a profit-making entity this should be emphasised.
- Clearly identifying the ways that the findings will be made available.
- Offering a range of methods of data collection (where feasible) eg offering the options of telephone, postal and web based survey. Different demographic groups may need to be targeted with different recruitment methodologies.
- A one page summary plain language statement should be provided alongside a longer (4-5 page) explanation for those who wished to have more information.
- Some individuals may have been motivated to participate by their knowledge of a serious disease or disability. Information materials should adequately describe, in lay terms the nature of the disease and the implications for sufferers of the disease. This may be particularly important for controls.
- Asking participants at the time of enrolment to studies to agree to be contacted for future surveys.”

Level of interest: An article of limited interest
Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:
I declare that I have no competing interests.